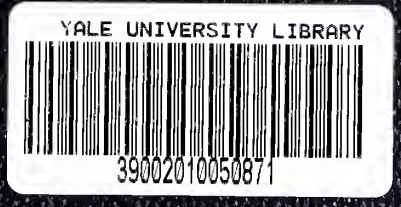

PATIENT UNDERSTANDING OF COMMONLY USED MEDICAL VOCABULARY

Richard D. Gibbs

1986

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PATIENT UNDERSTANDING OF COMMONLY USED MEDICAL VOCABULARY

A Thesis submitted to the Yale University
School of Medicine in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Medicine

by

Richard Dwight Gibbs

1986

ABSTRACT

PATIENT UNDERSTANDING OF COMMONLY USED MEDICAL VOCABULARY

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In order to assess patient understanding of commonly used medical language, 55 adult patients whose native language is English were randomly selected from among patients attending a medical outpatient clinic. The patients were asked to define 15 medical terms selected from patient education brochures available at the same clinic. Patients were scored on their correct responses to an oral questionnaire composed of the 15 medical terms. Patient scores were analyzed in relation to gender, race, age, level of formal education, and patient source of medical information. No association was found between patient performance on the test and gender, race, or age. Patient scores significantly improved with increasing years of education. In addition, those patients who gave reading (newspapers, magazines, and books) as their main source of obtaining medical information scored significantly higher than patients whose main source of information was visits to their doctor, television, or friends. In fact, patients giving these sources scored no better than patients who stated they had no source. A separate analysis showed that patients who gave reading as their source of medical information had significantly higher levels of education than patients giving other sources.

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INTRODUCTION

We live in an age where patient knowledge of medical terminology is increasingly emphasized. Formerly, it was hoped that patients understood enough common medical language and concepts to be able to communicate with their physician. Communication is the flow of information upon which diagnosis and treatment are based. It is the pathway for expressions of assurance and comfort. Communication is, and will remain, an essential ingredient in medical care. But a second reason for patients to be familiar with common medical language and concepts has become important -- prevention of illness through self-care by patients. We clearly hope for, and now even expect, a reasonable and healthy life-style from patients based on knowledge of health matters. The growing burden of medical costs, as well as ethical issues, has heightened the concern for patients to know more and play a more active role in their state of health.

Over the past 40 years, several studies have investigated patient understanding of commonly used medical language [1-9]. With today's increasing need for laymen to be adequately informed, it seems reasonable to reexplore the issue.

The purpose of this study is to assess whether the adult clinic patient of today has a workable understanding of words commonly used by health care professionals when talking to patients. A second purpose

is to assess the influence of race, age, gender, formal education, and source of medical information on patient level of knowledge. It is hoped that the results of the study might be of particular benefit to the professionals and patients of the clinic where the research took place.

PREVIOUS STUDIES

The first systematic investigation into patient understanding of medical terms was conducted by C.F. Redlich in 1945 [1]. A 1941 paper by J. Romano discussed the subject [2], but the earlier work lacks data and is mostly anecdotal. Redlich's purpose was to assess both the verbal and emotional responses of patients to commonly used medical terms and to analyze the patient-physician relationship in light of the study's results. The study population consisted of 25 men and women randomly selected from an adult, hospital based psychiatry practice. Deteriorated, psychotic, and aphasic patients were excluded from the study. All the subjects were born in the United States, all came from an urban environment, and most had at least 8 years of formal education. Within the format of a casual interview, the patients were asked to verbally define 60 medical terms selected from words frequently used by physicians during bedside rounds. Patient definitions were recorded verbatim and blindly scored by two physicians not involved in the interviewing.

A second aspect of the study looked at how each word affected the patients on an emotional level. Redlich considered a word properly understood when it evoked the intended emotional response as well as the appropriate verbal definition. Thus, based on observation by the interviewer, the words were assessed for the type of emotional reaction they elicited from the patients.

Results of the verbal definition part of the study showed that the average patient defined 30 percent of the words correctly; the range of patient scores was 10 to 63 percent. Redlich also assessed variables within the population that might influence patient scores. He found that although I.Q. correlated to higher patient scores, the educational level of the patient played no role. Although the study subjects were further characterized according to age, gender, occupation, and disease entity, no data were presented relating these variables to patient level of knowledge. Concerning the emotional responses to medical terms, it was found that each word fell into one of three general categories based on the type of response evoked: (1) words virtually unknown to the patients probably because of their technical nature (e.g., pathology, lesion, lues, metastasis); (2) words that gave rise to confusion and that were often incorrectly defined (tuberculosis, syphylis, paralysis, spinal fluid); (3) words that evoked a fear response (infection, tumor, mental disease, cancer, fit).

Redlich concluded that the majority of patients in his study were inadequately informed and had "striking misconceptions" concerning medical terms. He felt that the degree of patient misunderstanding was clearly enough to inhibit the physician-patient relationship. Furthermore, Redlich postulated that physicians may not be aware of the emotional effect that some medical terms have on patients. He expressed special concern for the careless use of words by physicians that evoke a fear response. such unawareness could not only result in failure to relieve a patient's anxiety and mental anguish, but could actually contribute to patient suffering.

In retrospect, Redlich made a considerable contribution to future investigations into patient understanding of medical language and concepts. His pioneering study was the first in this area of research to depart from conjecture and analytically quantify patient levels of knowledge. His method of collecting and scoring patient responses was straightforward and unbiased; later studies have extensively borrowed from his methods. And Redlich's assessment of variables within the population that might affect patient knowledge established a further precedent for future studies. Although each study that follows Redlich's has a slightly different emphasis, the variables of age, gender, race, and formal education have been consistently assessed in relation to patient knowledge. In Redlich's study, the lack of correlation between education and level of knowledge is of particular note; future studies uniformly disagree with this finding. For reasons that are not clear, I.Q. has not been assessed in relation to patient knowledge since Redlich's work.

When considering the overall mean score of Redlich's study subjects, one must keep in mind that 30 percent for correctly defined words applies only to Redlich's patients. Differences in time, local, and population characteristics preclude the extrapolation of any population's scores on such tests to a universal setting. Yet, one must not minimize Redlich's generality that his patients were poorly informed to a degree that compromises the physician patient-relationship. Inadequate levels of patient knowledge is a generality echoed in every study to follow.

It was not until 1955 that another study concerning patient understanding of medical vocabulary appeared in the literature. With the purpose of assessing whether indigent outpatients understood the language of

health care workers, G. Collins surveyed 100 antepartum women attending public health clinics in northwest Florida [3]. There were no criteria for patient selection, so that every cooperative woman on public welfare who came to the clinic on a given day was accepted into the study. Using an informal interview similar to Redlich's, Collins asked each patient to define 20 words commonly used in clinic brochures or in conversation by clinic workers in advising antepartum patients about dietary intake. The patient's answers were scored by the author herself "accepting any reasonable definition." In addition, the study subjects were characterized according to level of education and the amount of time spent reading and listening to the radio.

The results showed that 17 of the 100 patients understood 80 percent or more of the words; 55 patients understood 35 to 60 percent of the words; and 38 patients understood 50 percent or less. Words typically producing confusion were: "anemia" - confused with "enema" by 80 percent of the patients; "well-nourished" - defined as a "nervous body" by more than 50 percent of the patients; and "maternity" - defined as a type of dress by 50 percent of the patients. Both the level of education and ability to read appeared to positively influence the test scores, while listening to the radio seemed to play no role.

In discussing the results, Collins was hesitant to draw conclusions from a population with such a narrow profile. The study subjects were all women of child bearing age, on public welfare, and predominantly non-white. In spite of this limitation, Collins asserts that "the results are such that certain implications may be drawn and pertinent suggestions made which should be of assistance in working with such a group of patients."

For example, the average score was surprisingly poor in Collins's view, indicating that "although language may sound extremely elementary to the speaker, it is frequently confusing to the patient." Collins makes the suggestion that failure to follow dietary instruction possibly stems from not understanding the advice given, especially "when one considers that over one-fourth of these patients did not know which part of the egg was the egg yolk..." A patient's failure to follow medical advice because of misunderstanding language is supported by C.S. Rilely in 1966 [4]. Rilely investigated the extent to which British patients understood the dietary instruction given them by their physicians. Results revealed that well over one-half of the patients would eat contra-indicated foods because they had not understood some seemingly simple terms (e.g., protein, fat).

There are problems with the Collins study which the author herself recognizes in her discussion. The study population of young, indigent, non-white women is a narrow representation of outpatients in general. On the other hand, her study subjects are not unlike many indigent patients attending clinics throughout the country; Collins is correct in asserting that the studies results can act as a guideline in offering such patients medical care. Nevertheless, there are other problems with the methods of the Collins study. There was no random sampling when selecting the study subjects, the word list was limited to nutritional matters, the scoring was open to bias because the interviewer herself scored the answers, and no attempt was made to subject the results to any type of statistical analysis.

It should be noted that both Collins and Redlich were left with

the subjective impression that patients misunderstand common medical vocabulary to a greater degree than their physicians anticipate. Both authors suggest that such misunderstanding may contribute to failure in the treatment process. Of particular note is Redlich's finding that education played no role in the level of patient knowledge, while Collins suggests the opposite.

In 1957, Seligmann and group took a slightly different approach to the investigation of medical knowledge among patients [5,6]. Their purpose was threefold: to measure patient level of knowledge and factors that influence that level, to investigate how much physicians expect patients to know, and to analyze how the interaction between physicians and patients is affected by patient knowledge and physician expectations. Two-hundred and fourteen men and women were randomly selected from a population of outpatients with a heterogeneous mixture of medical problems. The patients were asked to complete a multiple choice questionnaire which measured their knowledge of ten relatively common diseases. In addition, the questionnaire recorded each patient's age, gender, personal experience with disease, highest grade in school, country of origin, and length of residence in the United States. The questionnaire was then presented to 89 physicians of the same clinic from which the patients were selected. For each question on disease, the physicians were asked to indicate if the correct answer should be known by patients, and secondly, to estimate the proportion of their clinic population that they felt did know the answer. A final aspect of the study was based on observation of the interaction between physicians and patients during patient visits to the clinic. The authors randomly selected 50 new appointment patients

and observed them and their physicians during several clinic visits. Notes were kept on the interaction between physicians and patients and all conversation was recorded.

Results of the study showed the patients to have a mean score of 55 percent for questions answered correctly on the multiple choice questionnaire. Age and sex had no effect on patient scores, while level of education significantly improved patient scores. No difference was evident between the scores of native or foreign born patients when comparable education was taken into account. One surprising finding was that having one or more of the diseases did not substantially increase a patient's knowledge of that disease in relation to patients free of the disease. On the other hand, patients with acquaintances who had a given disease did show significantly increased knowledge of that disease over the group as a whole.

Concerning physician responses to the questionnaire, the average physician was of the opinion that 83 percent of the questions should be known by patients. When indicating what patients actually did know, 81 percent of the physicians underestimated patient scores; they thought the patients would score lower than they did.

Concerning the final part of the study in which the authors observed the interaction between physicians and patients during patient visits to the clinic, several things were revealed. In general, the patients participated at an extremely low level with their physicians; one third never asked a single question, and the majority rarely requested that the doctor do anything nor directed the doctor's attention to anything.

It was also observed that those physicians who had seriously underestimated patient knowledge on the physician questionnaire tended to limit discussion with their patients. The physicians who were more accurate or who overestimated patient knowledge spent more time in discussion with patients.

The authors concluded that, in general, the study subjects were poorly informed about disease, and patient knowledge was "inadequate for optimal patient-physician cooperation in management of illness." Education tended to improve patient knowledge irrespective of age, gender, and country of origin. Several reasons were postulated as to why having a disease did not increase a patient's level of information on that disease. For one, patients may unconsciously reject explanations concerning his or her disease. Another possibility is that the physician may not adequately explain the condition to the patient due to the constraints of time or to the philosophy that patients are best kept uninformed. The increased level of knowledge found in patients who have acquaintances with a disease indicated to the authors that family and friends get better information than the patient. Implied in this idea is the possibility that physicians may speak with greater frankness to associates of patients than to the patients themselves.

In addition, Seligmann concluded that many physicians underestimate patient levels of knowledge. The physicians in his study had done so despite the actual low level of patient scores on the questionnaire. Based on his observation that physicians who underestimate patient knowledge also tend to limit their discussion with patients, Seligmann proposed the following scenario in which physicians themselves are partly to blame for poorly informed patients. Despite an already low level of

of patient knowledge, physicians often underestimate what patients do know. Perceiving that a patient is poorly informed, the doctor will tend to limit discussion with the patient because of the extra time and effort required for translation. The patient, lacking guidance from the doctor, interacts at an even lower level than he or she is capable. This only reinforces the doctor's original perception. The situation is a self-feeding circle which results in a decreasingly small amount of information shared between doctor and patient.

The conclusions of the Seligmann study are generally more applicable than earlier investigations because the sample population was large, and heterogeneous, and all correlations were based on statistical analysis. The study also differs from earlier work in its basic approach to the problem of miscommunication between physician and patient. Though both Redlich and Collins warn doctors to recognize and accommodate for low levels of patient knowledge, they do not implicate physicians as a cause for knowledge deficiency. Their focus remains on factors outside the immediate control of a physician-patient level of education, age, gender, race. But for the first time, the idea that physicians may share an etiologic responsibility for poorly informed patients is proposed.

In 1961, Samora et al., administered a test of medical vocabulary to 125 hospitalized patients in a U.S. hospital [7]. The study randomly selected adult surgical and medical patients, and the final study population varied in age, gender, cultural background, and disease entity. Using an interview and scoring format similar to Redlich's, the study subjects were asked to define 50 medical terms commonly used by physicians when talking to patients. Results showed that sex and age, when considered,

alone had no effect on patient scores, and education correlated positively with patient scores. In addition, Spanish Americans scored lower than white and black patients even when age and education were taken into account. No explanation was offered for this phenomenon, though one can postulate that it could be tied to cultural beliefs and customs. It is unfortunate that the authors did not define the length of residence in the United States of the study subjects. There is no indication of the proximity of the study subjects to medical systems of other lands. It may well be that Spanish Americans have more recently taken up residence in some American cities than blacks or whites.

The first study coming from outside the United States was conducted by Plaja and Samora at three Colombian outpatient clinics in 1968 [8]. It was a complex study with two purposes: (1) to measure patient knowledge of medical terms; (2) to investigate how communication between physician and patient is affected by the baseline attitudes and behavior of each.

Patient knowledge of medical terms was measured by adapting Samora's study of hospital patients [7] to 59 randomly selected adult outpatients. Demographic factors assessed were age, gender, level of education, and the patient's place of origin - urban versus rural. Results from this part of the study showed that only education had a significant affect on patient scores. Although patients from urban areas tended to score higher than those from rural areas, the difference was not significant.

The second purpose of the study, assessing the attitudes and behavior of both patient and physician during patient visits to the clinic, was accomplished by observation of patient-physician interaction. For each of the 59 patients, at least one visit with their physician was observed

with all conversation recorded. The authors stated that their goal in this part of the study was to analyze the "presentation of self" as a function of "social processes and cultural values governing the behavior of persons such as physicians and patients..." Before discussing their observations, the authors emphasized that they were focusing on factors that make a doctor unique as well as the more traditional consideration of patient make up. They expressed the idea that the years of molding and shaping in the esoteric world of medical training may create barriers between physician and patient which are as difficult to penetrate as the cultural or socioeconomic influences in a patient's background. One such barrier is the acquirement of a specialized vocabulary. Though necessary to facilitate communication between professionals, it leaves laymen in the dark.

The findings of this part of the study spoke well for the majority of the doctors involved. Relatively few problems appeared in physician-patient communication at the verbal level for the larger proportion of the population. The authors concluded that physicians and patients in the study interacted in a satisfactory manner, and that part of the reason for the good interaction was a physician readiness for patient lack of knowledge. Most of the doctors appeared to have been on the lookout for patient misunderstanding and had reworded and adjusted the conversation when necessary.

Plaja's conclusions were in contrast to Seligmann's observation that physicians tend to limit discussion when they perceive any deficiency in patient knowledge. There are many reasons for a discrepancy between the findings of these two studies. Among them are the different

nationalities of the physicians and patients involved, the difference in time between the two studies, and possible differences in financial incentives.

A final study to consider was conducted in Scotland by McKinlay in 1975 [9]. McKinlay's purpose was similar to the purpose of the Seligmann study: to measure patient levels of knowledge, to assess what physicians expect patients to know, and to analyze how the physician-patient relationship is affected by patient knowledge and physician expectations. In addition, McKinlay wished to determine if patients who regularly utilized the medical system differed in knowledge level from those who saw physicians infrequently. Eighty-seven women were randomly selected from among the working class maternity patients attending the obstetric service of a Scotish hospital. Those patients selected for the study were characterized as frequent utilizers of the medical system or underutilizers. Within each of these two groups, multiparous and primiparous women were identified. With an interview and scoring format similar to Redlich's, McKinlay tested each patient's knowledge of 13 words commonly used at the bedside by local obstetricians. McKinlay then administered a questionnaire to the local obstetricians in which they were asked to estimate what proportion of their patients would correctly define each word that had been used on the patient test. The physicians were also asked to indicate how much they actually used each word in discourse with patients.

Results showed that those patients who regularly utilized the medical system scored "consistently higher" than the underutilizers of the medical system. (The study makes no reference to statistical analysis.) Within the utilizer category, multiparous women scored higher than primiparous

women, although this difference was not evident in the underutilizer category. McKinlay concluded that the understanding of medical terms was increased by experience with the medical system.

Results from the physician questionnaire showed that the physicians tended to underestimate what the patients knew. When the physicians were asked how much they actually used each word in conversation with patients, a clear tendency was revealed for physicians to employ words without expecting the patients to understand their meaning.

In postulating reasons why a physician might knowingly use language that is beyond the patient, McKinlay referred to a 1964 paper by Skipper et al. [10]. Among the several untested hypotheses put forth, Skipper gives credit to the Seligmann theory that the constraints of time on a physician are prohibitive to simplification of language. Skipper goes further to state that the very act of communication may be in jeopardy due to the pressures of time. "The greater the pressure on hospital functionaries to achieve instrumental goals of care and cure, the less the probability they will communicate with patients except when it is defined as instrumental for care and cure." This sentiment brings to mind some of the core arguments centered around the present DRG system. Time is money, and saving money is a major impetus behind DRGs. Skipper's prophetic words create the frightening picture of an age when discussion with a patient is meated out in aliquots of minutes according to a schedule of disease entities. ("You may discuss diabetes for 8 minutes, but hypertension is permitted only 6.") A second hypothesis concerns the liability risk that is inherent to the practice of medicine. Skipper states that "The greater the need of hospital functionaries to protect

themselves from having errors and mistakes discovered in their performance of care and cure activities, the greater will be their restrictions on communication of information about their activities to patients." The 20 years since Skipper's paper have certainly shown a greater emphasis on physician liability. But steps to address the problem are leaning toward greater openness with patients rather than restricting communication. An example is today's emphasis on informed consent in language that is clearly understood by the patient.

In summary, all the studies reviewed here had the common goal of investigating patient knowledge of common medical language, either as vocabulary tests or as tests of the language that surrounds the more common diseases. In almost every case, the authors concluded that overall results indicated low levels of patient comprehension; perhaps low enough to jeopardize the treatment process through poor physician-patient communication. The one exception was the Plaja study of Colombian outpatient clinics. The majority of patients and doctors in this project indicated that verbal communication was not impaired by patient knowledge regardless of the level.

A secondary focus of all the works reviewed was an attempt to isolate factors that influence patient level of medical knowledge. Most of the studies found education to be the most influential factor to positively affect patient knowledge. Plaja found a tendency for patients with an urban background to have a higher knowledge level than rural patients. But the pattern was not strong enough to have significance. Only Redlich assessed I.Q., which he found to hold a positive correlation to patient level of knowledge. Age and sex failed to correlate with knowledge in all of the populations studied.

It should be noted that the populations studied were patients on medical assistance or working class people attending public clinics. A study of a more affluent white collar population remains to be done.

METHODS

I. Selection of Study Subjects

The potentially eligible study subjects were men and women over the age of 17 years who were registered patients in the Primary Care Center of the Yale New Haven Hospital. The Primary Care Center is an adult general medicine clinic which is located in the eastern urban center of New Haven, Connecticut. The clinic is affiliated with the Yale University School of Medicine and it serves a population which generally represents a lower socioeconomic level. Of the potentially eligible subjects, 53 patients were selected in the following manner. A roster of patients with appointments at the Primary Care Center was obtained at the beginning of each clinic day for a period of two and one-half weeks beginning October 9, 1985, and ending October 25, 1985. Only patients born in the United States whose native language was English were eligible; foreign born and patients whose first language was not English were excluded from the study. The names of the eligible patients were placed on a list and arbitrarily numbered. Those patients whose numbers appeared on a table of random numbers were approached on the day of their appointment and invited to participate in the study. The selection process continued until 50 patients agreed to participate out of a total of 53 patients selected. The selection process spanned 10 clinic sessions with an average of 5 patients agreeing to participate per clinic session.

II. Selection of Medical Words

The selection of the words was conducted by the principal investigator of the study. A total of 50 words was taken from patient education brochures that are made available to patients in the Primary Care Center. These brochures are written by organizations such as the American Heart Association, the Arthritis Foundation, the American Diabetes Association, and various pharmaceutical companies. A final list of 15 words was selected from the larger list of 50 words by arbitrarily choosing those that might be used by a physician or nurse in taking a routine medical history. An attempt was made by the author to select words that have one or both of the following qualities:

-words with universal application to any medical patient regardless of his or her disease history (abdomen, bowel, rectum, orally, sodium, infection, hereditary, symptom).

-words that refer to specific disease entities, but that are so prevalent in any population that they are routinely asked about when taking any patient's medical history (diarrhea, allergies, fracture, hypertension, diabetes, stroke, atherosclerosis).

III. Method of Administering the Word Test

The patients selected for each clinic session were approached by the principal investigator in the clinic waiting area where an explanation of the study was given and oral consent obtained. (See Appendix A for the format used in obtaining oral consent.) If the patient agreed to participate, he or she was taken to an unused office to administer

the word test. Only the author, who administered the test, and the patient were present during the testing.

The format used in testing each patient was a casual interview in which the patient was asked to verbally define 15 medical terms. The actual interview was conducted in the following manner. The author stated the word to be defined and then used the word in the context of a typical sentence. The same sentence for each word was used for every patient tested. (See Appendix B for the sentences used by the interviewer.) The patient was then encouraged to verbally define the word. The patient response was recorded verbatim in writing on a standard form completed by the author for each patient. (See Appendix C for an example of this form.) This process was repeated for each of the 15 words. Following the administration of the word test, the patient was asked to give his or her age, race, years of formal schooling, and gender. This information was also recorded on the patient's form. In addition, each patient was asked to relate which of the following sources played the largest role in providing him or her with information on medical matters:

1) Visits to Their Doctor - this category included physicians, nurses, and other personnel at the doctor's office.
2) Reading - this category included medically related articles in daily newspapers, magazines, and books.
3) Television - this included programs designed to educate the public in medical matters.
4) Associates and Friends - this means discussion with acquaintances.

5) None - this means that the patient felt he or she did not obtain medical information from any source.

The patient's response to main source of medical information was also recorded on the patient's form. At this point, the patient was thanked for participating in the study and the interview was concluded. Each interview lasted approximately 15-20 minutes.

IV. Scoring Patient Responses

The verbatim responses of the patients were scored independently by a senior medical student not involved in the interviewing. The scoring procedure was blind in that the scorer did not have access to any identifying or demographic data on the patients.

Patient responses were scored by placing them into one of three categories; this is an adaptation of the scoring procedure used by Redlich [2]. Category A corresponds to responses that reveal a workable understanding of the word. That is, no response was subjected to a strict dictionary definition. But if the response showed that the patient understood the interviewer's use of the word in the context of the example sentence, then the response was scored correct. For example, when patients were asked the meaning of the word "rectum" in the context of "bleeding from the rectum," general answers such as "opening in the rear" were accepted as correct. Though not a strict definition of the anatomical rectum, we do not think physicians intend for patients to distinguish between blood originating from the anus, the rectum, the sigmoid, or the descending colon when asked about "rectal bleeding." Category B corresponds to incorrect definitions together with definitions so vague

that the patient is misled by the word. An example of this type of response is describing "stroke" as "paralysis, coming from a breakdown of the heart." Category C corresponds to the patient having no knowledge of the word whatsoever so that no attempt was made at a definition.

V. Statistical Analysis

The difference in scores between male and female patients was compared with a two-tailed unpaired student's t-test. The same statistical procedure was used to compare the scores of non-white patients with white patients. One way analysis of variance followed by the Bonferroni t-test was used to compare multiple factors affecting patient scores (age groups, levels of education, sources of medical information).

RESULTS

Patient Population

Of the 50 patients that were selected and agreed to participate in the study, 64% were female and 36% were male. More than half of the patients were non-white (58%), while 42% were white. The age range was 18 to 80 years with a mean age of 54.9 years and a sample standard deviation of 17.8 years. The median age was 59 years. Formal education ranged from the second grade to completion of college. The mean years of school was 9.7 with a standard deviation of 3.4 years.

Patient Responses to the Words

Figure 1 shows a distribution of patient scores on the word test where score represents the number of words defined correctly by the patient. No patient defined all 15 words correctly, nor did any patient miss them all. The mean score for correctly defined words was 9.5 with a standard deviation of 3.0. Stated as a percentage, the mean patient score was 63%.

Figure 1

Distribution of Patient Scores

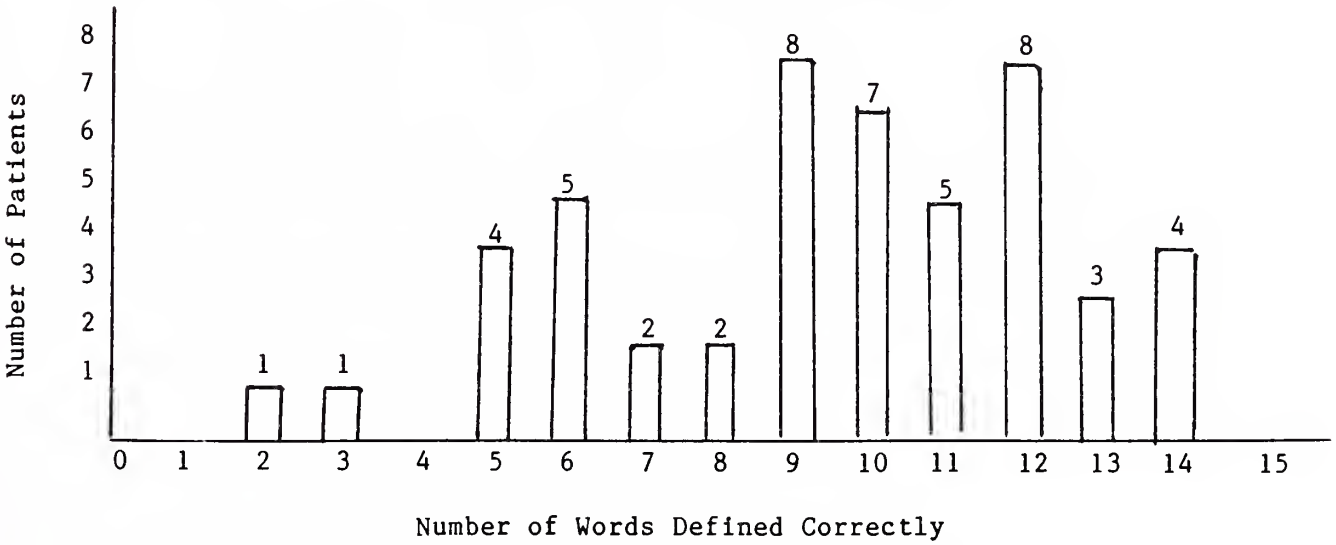


Table 1

Number and Percent of Correct and Incorrect Responses to 15 Words

Word	CORRECTNESS OF RESPONSE					
	A Correct		B Vague or Wrong		C No Knowledge	
	No.[a]	Percent[b]	No.	Percent	No.	Percent
Abdomen	35	70	11	22	4	8
Diabetes	43	86	5	10	2	4
Infection	43	86	6	12	1	2
Orally	31	62	16	32	3	6
Sodium	33	66	13	26	4	8
Rectum	44	88	4	8	2	4
Diarrhea	48	96	2	4	0	0
Hypertension	22	44	24	48	4	8
Atherosclerosis	2	4	9	18	39	78
Fracture	24	48	25	50	1	2
Symptom	39	78	7	14	4	8
Stroke	12	24	36	72	2	4
Allergies	43	86	4	8	3	6
Bowel	26	52	20	40	4	8
Hereditary	28	56	11	22	11	22
TOTAL	473	63	193	26	84	11

[a]No. refers to the number of responses for this word out of a total of 50 responses that fell into the given scoring category.

[b]Percent refers to the percentage of responses that were scored in the given category for this word.

Table 1 shows the number and percentage of "correct," "vague" or "wrong," and "no knowledge" responses for each word. The total figures at the bottom of each column reveal that 63% of all responses were scored as correct, 26% were scored as vague or wrong, and 11% of the responses were scored as no knowledge because the patient could not or would not venture a definition.

The word "diarrhea" was defined correctly more often than any other word (by 96% of the patients), followed by the words "rectum" (88%), "allergies" (86%), and "diabetes" (86%). The words receiving the greatest number of vague or wrong definitions were "stroke" (by 72% of the patients), "fracture" (50%), "hypertension" (48%), and "orally" (32%). The word "atherosclerosis" received the most no knowledge responses; 78% of the patients did not attempt a definition. Only 2 patients defined this word correctly.

Variables Affecting Patient Scores

Table 2 contains data which shows that patient scores are not affected by gender; there is no significant difference between female and male scores. Table 3 and Table 4 contain the data relating patient scores to race and age respectively. Neither of these factors had a significant affect on patient scores.

Table 5 contains the data relating patient scores to years of formal education. Here we see a factor that does significantly affect patient performance on the word test. Column A shows that the percentage of correct responses increases as the level of patient education increases. The percentage of vague or wrong responses (Column B) decreases with

increasing education as does the percentage of no knowledge responses (Column C). The difference in patient scores between the various educational levels is significant for a $p<0.05$, with the exception that the score for the 7-9 years of school level did not significantly differ from the <7 year level.

Table 2

Correctness of Response According to Gender of Respondents*

	Correctness of Response					
	A Correct		B Vague or Wrong		C No Knowledge	
Gender	No.[a]	Percent[b]	No.	Percent	No.	Percent
Total (n=50)	9.5	63	3.9	26	1.6	11
Male (n=18)	8.8	59	4.2	28	1.9	13
Female (n=32)	9.7	65	3.7	24	1.6	10

* Differences in mean number of correct responses between male and female population was not found to be significant ($p>0.05$).

a No. refers to mean number of responses for that gender in the given scoring category.

b Percent refers to the mean percentage of responses for that gender in the given scoring category. All percentages have been rounded to the nearest whole number.

Table 3

Correctness of Response According to Race of Respondents*

	Correctness of Response					
	A Correct		B Vague or Wrong		C No Knowledge	
Patient Population	No.[a]	Percent[b]	No.	Percent	No.	Percent
Total (n=50)	9.5	63	3.9	26	1.6	11
White (n=21)	9.9	69	3.2	21	1.4	10
Non-white (n=29)	8.8	59	4.3	28	1.8	13

* Differences in mean number of correct responses between white and non-white populations was not found to be significant ($p>0.05$).

a,b Please see TABLE 2.

Table 4

Correctness of Response According to Age of Respondents*

	Correctness of Response					
	A Correct		B Vague or Wrong		C No Knowledge	
Age	No.	Percent	No.	Percent	No.	Percent
Total (n=50)	9.5	63	3.9	26	1.6	11
< 40 yrs. (n=11)	10.4	68	3.3	22	1.3	9
40-65 yrs. (n=22)	9.8	65	3.7	24	1.5	10
> 65 yrs. (n=17)	8.4	56	4.5	30	2.1	14

* There was no significant correlation found between age and mean number of correct responses ($p>0.05$).

a No. refers to the mean number of answers for that age group in the given scoring category.

b Percent refers to the mean percentage of responses for that age group in the given scoring category. All percentages have been rounded to the nearest whole number.

Table 5

Correctness of Response According to Educational Level of Respondents*

	Correctness of Response					
	A Correct		B Vague or Wrong		C No Knowledge	
Years of School completed	No.	Percent	No.	Percent	No.	Percent
Total (n=50)	9.5	63	3.9	26	1.6	11
<7 years (n=9)	5.6	37	6.1	41	3.3	22
7-9 years (n=13)	8.5	57	4.3	29	2.2	15
10-12 years (n=21)	10.6	71	3.3	22	1.1	7
13-16 years (n=7)	12.7	85	1.7	11	0.6	4

* Analysis of variance shows the levels of education to significantly affect performance on the word test ($p<0.01$). Multiple comparisons between the levels of education show that the mean number of correct responses increases significantly ($p<0.05$) with each increment of education, with the exception that the 7-9 year level does not significantly differ from the <7 year level.

a No. refers to the mean number of responses for that educational level in the given scoring category.

b Percent refers to the mean percentage of responses for that educational level in the given scoring category. All percentages have been rounded to the nearest whole number.

Table 6 contains data relating patient scores to the source from which the patient receives his or her medical information. Under the column headed Source of Information, it can be seen that encounters with health care professionals during "visits to doctor" was given as the main source by 22 patients (44%). Reading medically related articles in newspapers, magazines, or books was cited as the main source by 12 patients (24%). Television shows concerned with educating the public on medical matters was listed by 8 patients (16%), while 4 patients (8%) stated they learned the most from talking with "associates and friends." Four patients (8%) stated that they had no source which provided them with medical information. A comparison of the five sources revealed that those patients who claimed reading as their main source of information scored significantly higher on the test than the other groups. None of the other sources had an effect on test scores.

Table 6

Correctness of Response According to Patient Source of Medical Information*

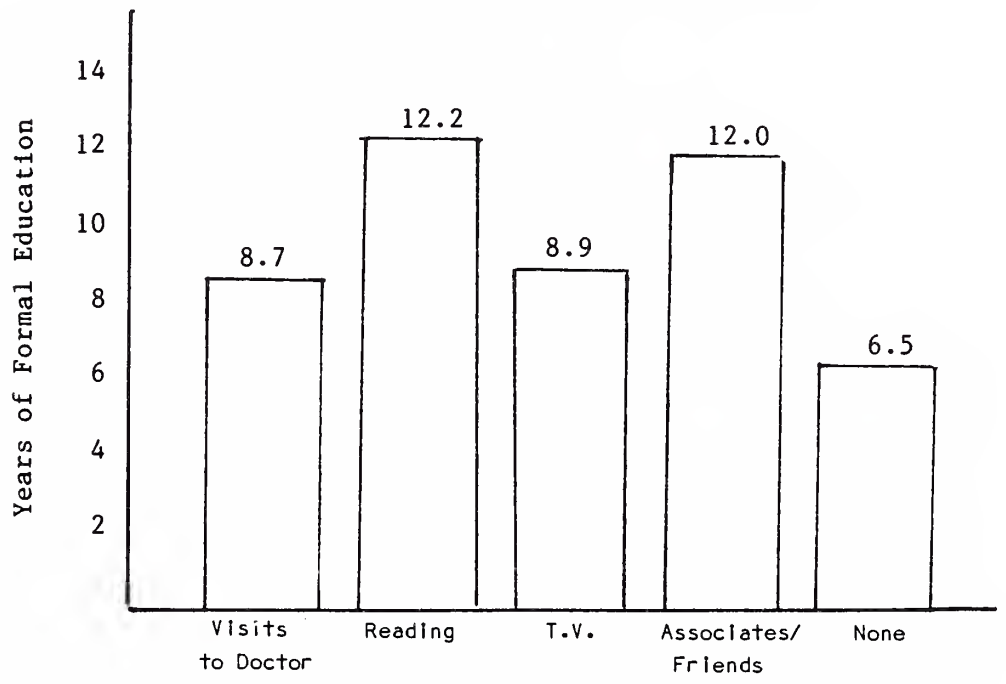
Source of Information	A Correct		B Vague or Wrong		C No Knowledge	
	No.	Percent	No.	Percent	No.	Percent
Total (n=50)	9.5	63	3.9	26	1.6	11
Visits to Doctor (n=22)	8.6	57	4.3	29	2.0	13
Reading (n=12)	12.1	81	2	13	0.9	6
Television (n=8)	8.5	57	5.3	35	1.2	8
Associates and Friends (n=4)	7.3	48	4	26	3.7	26
None (n=4)	7.7	52	4	26	3.3	22

* Analysis of variance showed that the various categories of obtaining information on health care matters affected patient performence to a significant degree ($p < 0.01$). Multiple comparisons between the categories showed that patients who claimed to obtain information by reading had a significantly higher number of mean correct responses than any other method of obtaining medical information ($p < 0.05$).

Because the results of the study indicated that test scores were influenced by the educational level of the patient as well as the patient source of obtaining medical information, a separate analysis was performed looking for a relationship between these two variables. Figure 2 contains data relating patient source of medical information to years of formal education. Those patients who gave "reading" as their main source had an average of 12.2 years of education. This was significantly higher than the 8.7 years of school in the group that cited "visits to doctor" as their main source of information. The educational level of the "reading" group was also significantly higher than the patients who gave "none" as a source of information (12.2 years compared to 6.5 years). The differences between the "reading group," the "television group," and the "associates/friends group" were not found to be significant.

Figure 2

Patient Source of Medical Information as it Relates to Mean Years of Formal Education



DISCUSSION

Mean Level of Patient Knowledge

A striking aspect of the study's results is the relatively low mean score of the study population. On first impression, the mean score of 63 percent may seem quite adequate for laymen tested on medical vocabulary. This might, after all, fall into the "passing" category on typical school examinations. But on further reflection, 63 percent in this case implies that almost 4 common medical words out of 10 are misunderstood by the average American-born patient in the clinic studied. If one accepts that the words on the test are typical of those used by health care professionals when talking to patients, then the 63 percent means that a good deal of what professionals say is lost to the patient.

The question of whether health care professionals actually do use the words on the test when talking to patients presents somewhat of a problem. There is no objective way of making this determination without carefully documented observation or recordings of conversation between professionals and patients. Thus, some uncertainty remains concerning the validity of testing patients on these specific words. On the other hand, we know that the organizations producing the brochures (i.e., the American Heart Association) use these words when addressing patients. We also hear words on this level on television, we read them in laymen magazines and newspapers, and we can assume that at least some physicians use language on the level of "orally," "sodium," and "hypertension"

when talking to patients. The words are in common enough usage to allow the possibility that patients may misunderstand much of what is said to them in the clinic situation.

Variables Affecting Patient Knowledge

With one exception, the assessment of population variables in relation to patient level of knowledge provided predictable results. The results of this study are in agreement with previous studies which have consistently shown that gender, race, and age do not influence patient knowledge of medical vocabulary or concepts [5,6,8,9,10]. The finding that increasing education positively influenced patient performance on the test was also to be expected. Earlier studies solidly support the common sense notion that formal education improves patient knowledge [3,5,6,8,9,10]. The fact that this study found no significant difference in patient scores between patients with 7 years of school and those with 7-9 years of school can probably be attributed to the small number of patients (n=9) and the large standard deviation (2.6 years) in the 7 year group.

The one variable that affected patient level of knowledge in an unexpected manner was the patient source of medical information. The data showed that patients who gave "reading" as their main source scored significantly higher than patients who cited "visits to their doctor." This in itself is not surprising; several reasons can be postulated as to why patients who read might display more knowledge than those who rely on medical personnel at their doctor's office for information. For example, the data show that readers have significantly more education than other groups. It has already been determined that higher education

is associated with higher scores, thus, education may be the basis for any significance attributed to the group that reads. The converse can also be postulated - reading may be the determinate factor among the patients who scored higher on the test. Reading has the advantage of being a daily activity while clinic visits are only occasional events. It will require further study to determine if higher scores among the reading group are due to factors associated with the act of reading itself or to the fact that readers simply have a higher base line level of education. Whichever the case may be, one can reasonably accept that readers score higher than those depending on clinic visits for medical knowledge. The sobering thought is that those who gave the doctor's office as their main source did not score significantly better on the test than those patients who claimed no source of obtaining information. The reasons behind this finding are not clear. Yet, these results might serve as an indication that the clinic situation, along with all other sources that provide medical information, might play a more effective role in raising patient levels of knowledge.

One thing must be kept in mind when considering patient source of medical information. This data is subjective, for the information collected was the patients' own opinion of where he or she might have learned the most about health care matters. This cannot be taken as a measure of where patients actually do learn the most; rather it is a measure of patient bias toward the subject, and the results should be viewed with some caution.

Patient Responses Fall Into Patterns

One of the more interesting considerations concerning the results has to do with the words on the test. In reviewing patient responses to specific words, the following patterns are evident:

1. Diabetes, Diarrhea, Allergies - The fact that these words were defined correctly more often than any of the others probably reflects their prevalence as entities in the population. The implication is that patients may have a useful working knowledge of diseases and concepts with which they have some personal association. For example, although many of the patients did not have diabetes, most of them knew a family member or friend who did have the disease.

2. Atherosclerosis - This word was correctly defined by only 2 out of 50 patients. It received 9 "wrong or vague" definitions, most of which had to do with the "liver" (as in "sclerosis of the liver"). The fact that 78 percent of the patients ventured no definition whatsoever indicates that this word may be too technical to be in common use with patients.

3. Hypertension - Nearly 1 out of 2 patients (46%) defined this word as "nervous" and "easily upset." One might guess that the high prevalence of hypertension as a disease would have led to a greater number of correct responses (as "diabetes" did). However, "hypertension" has the great disadvantage of literally meaning "nervous" when broken down into parts - HYPER and TENSION.

4. Stroke - This was the second most commonly missed word. Unlike "atherosclerosis," the problem was not lack of familiarity due to the technical difficulty of the word. Most of the patients thought they

knew what it meant, but 72 percent of the responses were "wrong or vague;" of these, two-thirds associated the word with "paralysis" but stated that it was the same as a "heart attack." That is, they felt heart attack is the process that causes paralysis.

5. Fracture - Forty percent of the patients thought this meant "not a broken bone" but rather "a cracked or chipped bone." When further questioned as to whether they would inform their physician of a previous "complete break" if asked about a "fracture," the majority of patients said they would not.

6. Orally - One out of 4 patients thought this word meant "how often" one takes medicine. For example, some said it meant "daily," and some said it meant "every few hours" with the actual number to be specified by the doctor.

7. Sodium - Sixty-six percent of the patients knew it meant table salt when used in the context of diet. Of the remainder, two-thirds thought it meant multiple items in the diet (e.g., "sugar, fats, salt, and the like"), and one-third had "no knowledge" of the word.

8. Bowel - One out of 4 patients defined bowel as the process of "passsing stool." The confusion, no doubt, arises from the well known phrase "bowel movement." These patients were quite baffled by the idea of cancer in the large bowel.

A Final Word

When interpreting any of the results of the study, it should be kept in mind that the population was selected from clinic patients born in the United States whose native language is English. This was done

to simplify the analysis of other variables such as age, race, gender, and source of medical information. But there is a price paid for arbitrarily making the language qualification; the population studied is not typical of most clinics associated with teaching hospitals that provide care to indigent patients. For example, Spanish speaking people were not a part of the study, while they are very much a part of many medical clinics around the country. Nevertheless, the study's conclusions should be useful, for the real value of the study is that it calls attention to the surprising degree to which patients misunderstand common medical language. This general conclusion would only be more strongly reinforced if patients had been included in the study who do not speak English or who recently learned English.

In summary, a group of English speaking patients was tested on medical words assumed to be in common usage by health care professionals when talking to patients. The mean level of patient knowledge was relatively low irrespective of variations in age, gender, or race. Although higher levels of education and reading as a source of obtaining medical information were both factors that improved patient performance on the test, the overall implication is that the average patient at the clinic studied may suffer from poor communication with their health care providers. Patient ignorance may also contribute to poor self-care on the part of the patient. Thus, the chance of a healthier life through preventive medicine is diminished. It is clear that many directions can be pursued to raise the level of medical knowledge among patients. Possibilities include increased effort towards educating laymen in medical matters by schools, government agencies, businesses, hospitals, and clinics.

But these are complex measures that require planning, funding, and most of all, time. Meanwhile the burden lies with health care professionals. They must anticipate low levels of knowledge from patients. They must be the ones to adjust accordingly.

REFERENCES

1. Redlich, C.F., "The Patient's Language, an Investigation Into the Use of Medical Terms." Yale J. Biol. and Med., 1945; 17,No.3: 427-453.

2. Romano, J., JAMA, 1941; 117: 664-667.

3. Collins, G.E., "Do We Really Advise the Patient?" J. Florida Med. Assoc., 1955; 42: 111-115.

4. Riley, C.S., "Patient's Understanding of Doctors' Instructions." Medical Care, 1966; 4: 34-37.

5. Seligmann, A., Pratt, L. et al., "Level of Medical Information Among Clinic Patients." J. Chron. Disease, 1957; 6: 497-509.

6. Pratt, L., Seligmann, A. et al., "Physicians' Views on the Level of Medical Information Among Patients." Am. J. Public Health, 1957; 47: 1277-1283.

7. Samora, J. et al., "Medical Vocabulary Among Hospital Patients." J. Health Hum. Behavior, 161; 2: 83-92.

8. Plaja, A.O. et al., "Communication Between Physicians and Patients in Outpatient Clinics." Milbank Memorial fund Quarterly, 1968; 46: 161-213.

9. McKinlay, J.B., "Who is Really Ignorant - Physician or Patient?" J. Health Soc. Behavior, 1975; 16(1): 3-11.

10. Skipper, J.K. et al., "Some Possible Consequences of Limited Communication Between Patients and Hospital Functionaries." J. Health Hum. Behavior, 1964; 5: 34-40.

APPENDIX A

ORAL CONSENT FOR PARTICIPATION IN A STUDENT RESEARCH PROJECT

YALE UNIVERSITY SCHOOL OF MEDICINE

Patients will be approached while waiting for their appointments in the Primary Care Clinic. A spoken request will be made for their agreement to participate in the project. There will be no form for them to read and nothing to sign. The request will be made as follows:

Hello! - I am a fourth year medical student here at Yale, and I'm conducting a study on medical vocabulary. If you could spare a few minutes of your time, it would help the study a great deal for you to be a part of it. I am asking you to participate simply because your name came up in a random draw of the people coming into the clinic today. What I would like to do is ask you the meaning of about 15 words that doctors and nurses commonly use. It is <u>not</u> any kind of intelligence test or measurement of your ability. It is a study to see if the words we use here are understood by the patients who come here. I do not need to record your name or hospital number, nor will you be asked to sign anything. All participants in the study will remain entirely anonymous. But I would like to record your sex, age, level of formal education, and how you come across health information (T.V., magazines, newspapers, etc.).

This study may be of no direct benefit to you at this time; nor will you be paid to participate. But hopefully it will benefit patients in the future by helping health care people who work here to know if we are communicating well enough with the patients.

You are free to choose not to participate in the study, and if you do participate, you are free to stop at any time in the interview.

If you have any questions about anything I have said, the study itself or the role you would play in it, please feel free to ask them. If not, then would you like to participate, and do I have your permission to record your definition of the words in the study?

APPENDIX B

(CONTEXT WITHIN WHICH THE WORDS WERE ADMINISTERED TO THE PATIENTS)

ABDOMEN	-	Do you have pain in your abdomen?
DIABETES	-	Does anyone in your family have diabetes?
INFECTION	-	Have you had any recent infections?
ORALLY	-	You are to take this medicine orally.
SODIUM	-	You must lower the sodium in your diet.
RECTUM	-	Do you ever bleed from your rectum?
DIARRHEA	-	Certain foods will cause some patients to have diarrhea.
HYPERTENSION	-	Patients with hypertension must take their medicine regularly.
ATHEROSCLEROSIS	-	Diet may be helpful in preventing atherosclerosis.
FRACTURE	-	Have you ever had a fracture?
SYMPTOM	-	Are you experiencing any symptoms?
STROKE	-	Exercise may help lower the risk of stroke.
ALLERGIES	-	Do you have any allergies?
BOWEL	-	Cancer can sometimes strike the large bowel.
HEREDITARY	-	Some diseases are hereditary.

APPENDIX C

STANDARD FORM FOR VERBATIM PATIENT RESPONSE

PATIENT INTERVIEW NO. _____ CLINIC NO._____

SEX_____ AGE_____ RACE_____ YEARS OF SCHOOL_____

SOURCE OF MEDICAL INFORMATION: 1._____

2._____

3._____

4._____

ABDOMEN

DIABETES

INFECTION

ORALLY

SODIUM

RECTUM

DIARRHEA

HYPERTENSION

ATHEROSCLEROSIS

FRACTURE

SYMPTOM

STROKE

ALLERGIES

BOWEL

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